

CITIZEN ACCESS TO HEALTH DATA

An international review of country approaches to citizen access to health data



GLOBAL DIGITAL HEALTH
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Suggested Reference

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CITIZEN ACCESS

GDHP White paper on Clinical and Consumer Engagement

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NOTE FROM CHAIR, CLINICAL AND CONSUMER ENGAGEMENT WORK STREAM

I am pleased to submit this report on behalf of the Clinical and Consumer Engagement Work Stream of the GDHP.

The initial deliverable of this work stream, published in 2019, focused on the key enablers and barriers that contribute to successful clinician engagement in the design and implementation of digital health programs. The focus of this report is on the consumer. Specifically, we were interested in exploring global efforts around making personal health information available to citizens. This area was of particular interest for two reasons. First, it represents a relatively new phenomenon. Over the last decade there has been a universal shift in thinking; one where there was little to no support for providing citizens with access to their information, to present day, where we are accelerating efforts to provide citizens access to information in an equitable and secure manner. Second, because most countries are just beginning this citizen access journey, this is an excellent opportunity to share our collective knowledge and actively pursue global efforts, especially around common metrics to assess and measure impact.

This report, which includes input from 22 nations around the world, identifies some of the key drivers for providing citizen access to their personal health information, explores their impact and articulates key success factors for driving adoption. The survey data is supplemented by case studies that provide meaningful and tangible examples and best practices.

Key findings of this report support the literature that confirms citizens want access to their health information and are more empowered and satisfied when they have it. The report identifies a gap in some countries between the number of citizens who can access their health information and the number that do access it. Furthermore, it suggests that ensuring that available information is useful to citizens (accomplished through co-design and other means) and that they have digital literacy skills is important. The report also speaks to the general difficulty in measuring the impact of citizen access to their health information and suggests that this might represent an excellent opportunity to develop global indicators and measures.

I would like to offer my sincere thanks to all contributors who completed the survey, shared their insights and experiences, and/or submitted case studies for this report. Without you this report would simply not have been possible. A special thank you also to Simon Hagens and Ellie Yu, principal writers of this report.

I look forward to further discussion around this important topic and trust that these findings will be of value to all GDHP member countries.

Shelagh Maloney Chair Clinical and Consumer Engagement Work Stream, GDHP

Executive Vice President, Engagement and Marketing, Canada Health Infoway

1 EXECUTIVE SUMMARY

This report provides evidence derived through a survey on the state of citizen access to personal health information (PHI) in GDHP participant countries and territories. The survey responses present a view on the progress and impact being made across a diverse group of 22 countries and territories in the implementation of technology solutions to improve citizen access to health information.

Citizen access to personal health information is reported as broadly available by over 30 per cent of the respondent countries (seven of the 22 responses), and available to most people in an additional over 20 per cent of respondent countries (five additional responses). Adoption uptake by people has been gradual, with four countries estimating 25–50 per cent of their population are users (that is, those who have accessed their information online), with others reporting that less than a quarter of their population has accessed their personal health information electronically. Many countries and territories remain in the early phases of implementation and adoption. The survey results indicate a gradual adoption process, and this is consistent with published evidence around uptake of consumer solutions. The types of information available to people vary across respondents. Medication information, immunisation records and diagnostic test results were reported to be the most commonly available information.

Most respondents report taking a blended approach to implementing citizen access solutions meaning certain services are available on a coordinated or national basis while other services are available at an institutional or provider basis. Only approximately 40 per cent of the respondents report taking only a coordinated approach to providing citizen access (that is, reaching all citizens with a single solution). Despite the current majority among respondent countries and territories taking a blended approach to providing citizen access, the qualitative responses of many countries stressed the benefits of having a national solution. Some countries taking a blended approach described future strategies for a national solution. These strategies vary in form and include policy frameworks, technology solutions, and national portals for access.

The most common drivers reported by participant countries and territories that propel them to provide people with access to their personal health information is to improve patient engagement and empowerment and to satisfy public demand and the patient-centred agenda. On the other hand, improving health system efficiencies and avoiding unnecessary visits were not viewed as key drivers to providing citizens with access to their personal health information. The driving force of patient-centred care and patient empowerment is consistent with the current ideology according to which access to personal health information is viewed as a cornerstone of a successful health care system. The debate has shifted from “should people have electronic access to their information” to “how do we best deliver electronic access”.

The most impactful change associated with providing citizens with access to their personal health information is more engaged patients reported by half of the respondents. This is followed by improved public satisfaction and avoided visits or calls as other positive changes. These results are generally consistent with the literature; however, qualitative responses caution the interpretation of these results with cautionary caveats around data quality, premature measurement strategies, and potential biases that impact the areas most studied. Broadly, there is a sense of emerging value experienced from access to their personal health information by citizens, but also

the need for greater focus on analytics and measurement to properly evaluate, learn, and optimise.

An effective coordinated approach to providing people with access to their personal health information is paramount for harvesting the benefits from the use of health data to improve healthcare systems. The work of the Clinical and Consumer Engagement Work Stream on citizen access to personal health information provided an initial view of the global landscape and important insights into the reach of citizen access, its drivers and impacts, as well as many topics of importance that warrant future consideration beyond the current scope of this white paper. This work could be augmented through a range of tangible activities including:

- Sharing of national implementation strategies to enable the dissemination of successful use cases and case studies;
- Exploring changes for clinicians as people access to their personal health information, including clinician influence on patients, roles and workflows, and how clinicians can be best engaged to ensure success;
- Comparing challenges encountered by countries, and solutions that have been employed to overcome these challenges; and
- Sharing methodologies for measuring the impact of citizen access on patient experience, clinical workflow, and the healthcare system more broadly.

Regardless of the challenges and the unknowns, this analysis demonstrates that the shift towards people accessing their own personal health information is now underway in countries and territories around the globe. With most responding countries and territories still at the beginning of this journey, the opportunities for international collaboration are abundant.

2 BACKGROUND AND METHODOLOGY

2.1. WORK SCOPE

The initial work of the GDHP Clinical and Consumer Engagement Work Stream was spent examining aspects of clinical engagement. Over the past year the Work Stream focussed on examining the changes that have resulted and/or may result from citizen access to personal health information (e.g. how information is collected, shared and used). Specifically, the Work Stream aims to develop an understanding of 'the impact of citizens access to their personal health information', which has created an unprecedented level of data transparency.

Citizen access to their personal health information has become a common objective and activity in many health service organisations and governments around the world. There is a broad scope of desired impacts for citizens including increased satisfaction, more engagement/empowerment, time saved and specific health outcome improvements. Health system resource improvements, avoiding unnecessary care and other efficiencies for health system and governments have also been cited as benefits. There are unintended impacts as well, with some needing to be managed. Critical to optimising the value from these tools is to be able to clearly understand the achievable goals from providing citizens with access and the pathways towards achieving them. This white paper will draw upon experiences around the world to assist in building a strong common understanding of impacts anticipated and realised.

The white paper also endeavours to provide a point-in-time snapshot of the state of deployment, availability and adoption of access to personal health information by citizens in order to provide context for understanding the impacts and the state of the evidence in this rapidly evolving domain.

To inform the white paper, the GDHP invited input from participants around the world, and received submissions from 22 jurisdictions, providing a rich evidence base to share. These submissions came from:

- Australia
- Argentina
- Austria
- Brazil
- Canada
- Estonia
- Hong Kong SAR
- India
- Indonesia
- Italy
- Japan
- The Republic of Korea
- Netherlands
- Poland
- Portugal
- The Kingdom of Saudi Arabia
- Singapore
- Sweden
- Switzerland
- Uruguay
- The United Kingdom
- The United States

2.2. PROBLEM STATEMENT

The evidence is clear that citizen access to their personal health information can improve patient activation, empowerment and participation in care, which could have promising impacts on health outcomes.

Access to personal health information may include access to test results, clinical notes or summaries, medication records, etc., and may also be offered in conjunction with other electronic services such as electronic booking of appointments, virtual visits, contributing information, electronic medication prescription renewal, etc.

As technology continues to enable data transparency and data sharing between parties, what are the implications, both positive and negative of this increased access?

2.3. METHODOLOGY

The development of the white paper was led by the GDHP Clinical and Consumer Engagement Work Stream. The group met regularly to define the problem and support the authoring team.

GDHP participant countries and territories were invited to participate in the landscape analysis by responding to a survey on citizen access to their personal health information. The survey asked questions under three main categories:

1. The current state of citizen access
2. Drivers for investments in providing people with access
3. Impact of providing access

The survey consisted of both close-ended and open-ended questions (see Appendix A for a copy of the questionnaire). Complete responses were received from 22 participant countries and territories. The responses to these questions were synthesised and are presented in the results and discussion sections of this report. A systematic analysis was undertaken to draw out common themes. Additional literature scans were conducted to identify the current state of evidence described by GDHP participants. These were informally scanned leveraging recommendations from responding countries and territories. Searches were conducted by Canada Health Infoway for planning and research purposes. Relevant publications are incorporated into the white paper (see the References section). The white paper was member-checked by respondents for validation and contribution of additional details.

To fully understand and appreciate the efforts of survey respondents to provide citizens with access to their personal health information, it is important to have some insights into how their health systems are arranged, how they are governed, and how health services are funded and delivered. Appendix B provides a general overview of each country's health system governance model as well as advances they have made with electronic health records.

2.4. LIMITATIONS

The GDHP is an international collaboration and consists of countries and territories that are at varying maturity levels in terms of developing approaches to provide people with

access to their personal health information. In this report, we tried to provide a generalisation of countries' status in terms of where they are at in providing people with access to their personal health information. That said, we recognise that there are intra-jurisdictional variations in terms of the degree of penetration, adoption, and utilisation of electronic personal health information access. In addition, there may be other national approaches to this topic among GDHP participant countries and territories that are not described in the English language literature and are therefore not included here.

With the exception of a few external references, the majority of the findings reported here come from the submissions and commentary of participating countries, in most cases provided by one or a few country/territory representatives. We acknowledge that there may be omissions or inaccuracies from these reports. The submissions only represent a sample of countries and territories, most of which have made significant efforts to apply digital health, and do not represent a global picture.

Many important topics relating to citizen access were identified, but this white paper has a narrow scope and does not represent a comprehensive view.

The analysis and authoring were conducted primarily by a working group at Canada Health Infoway. Guidance and support from the Secretariat included meetings to confirm methodology, distribution of the survey tool, and communication with many responding countries and territories. The working group reviewed plans and deliverables periodically, providing important insights during the authoring of the white paper.

3 RESULTS: OVERVIEW OF CURRENT STATE OF ACCESS

3.1. AVAILABILITY OF ACCESS

The majority of GDHP participant countries and territories that completed the survey reported that electronic access by citizens to their personal health information is available to all or most users. One-third of the respondents suggested that electronic access to personal health information is available to some or few of their citizens.

Participating countries where electronic access to personal health information is broadly available include Australia, Austria, Estonia, Portugal, the Kingdom of Saudi Arabia, the United States, the United Kingdom, and Sweden (see Table 1). This finding is consistent with previous research findings on access to personal health information and the expansion of electronic medical records (EMRs).

Table 1: Availability of access by citizens to PHI by survey respondent

Broadly available to all	Available to most	Available to some/few	Access to PHI planned, not deployed
Australia	Canada	Argentina	Kingdom of Saudi Arabia
Austria	Hong Kong SAR	Brazil	
Estonia	Italy	India	
Portugal	The Netherlands	Indonesia	
Sweden	Singapore	Japan	
United Kingdom		Poland	
United States		Republic of Korea	
		Switzerland	
		Uruguay	

3.2. WHAT INFORMATION IS AVAILABLE

The survey asked respondents to report what kinds of information are made available to people electronically. Access to medication information is reported as the most available kind of information (see Figure 1). Outpatient, community or primary care records are reported as the least available kind of information.

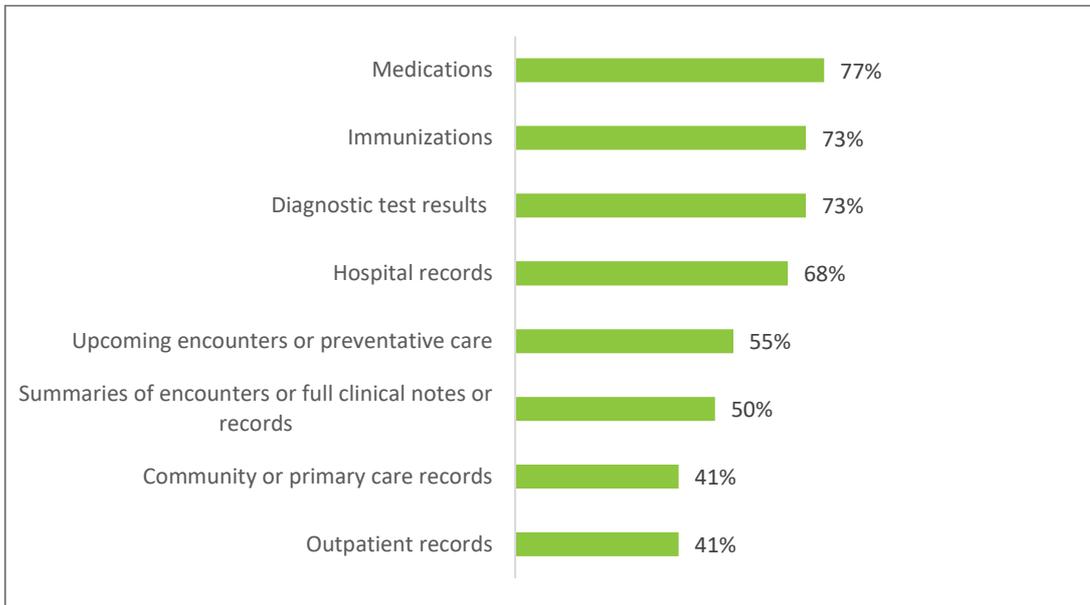


Figure 1: Percentage of respondents responding “yes” to the types of information that are most commonly available to people (N=22)

3.3. ADOPTION RATE FOR CITIZEN ACCESS

While personal health information has gradually been made available to citizens in many responding countries and territories, adoption of these services has taken a longer period to develop. The adoption rate of access to personal health information attempts to understand approximately what portion of people actually have access their personal health information (for example, viewed, downloaded, forwarded information accessible at least once). There seems to be a gap between availability and adoption for most GDHP participants which is reflected in the percentage gap between availability and adoption rate.

The gap between availability and adoption indicates the need to actively engage, educate and promote the availability of personal health information, above and beyond making information available. Understanding accurately the adoption rate of citizen access to personal health information electronically is difficult as the data sources for the adoption rate can be limited and complex. One participant was able to measure the number of views, while another measured the number of downloads, and another measured the number of accounts created. The diversity in the measurement strategies introduce heterogeneity in the definition and measurement of adoption rate. Adoption rate measurement differed across jurisdictions, with estimates sourced from transaction data, surveys and other available data. Despite these limitations, countries and territories could be grouped into ranges with a reasonable level of certainty.

The category with the highest approximate level of adoption rate includes Estonia, the United States, Sweden, and Australia. Estonia reported the personal health information adoption rate at 50 per cent, which is the highest among all survey participants. Sweden and the United States both reported an adoption rate of approximately 30 per cent. As at March 2020, Australia reported over 90% Australians had a My Health Record – Australia’s national health portal where citizens can access their information. The next category of participants, which is the largest group, reported adoptions rates between 5 per cent to 25 per cent. This group includes countries such as Canada at 20 per cent, Uruguay at 14 per cent, Portugal at 22 per cent, Singapore at approximately 15 per cent, and the United Kingdom which reports 15 million users. In Italy and Netherland, adoption rates vary by region. The third category of respondents reported adoption rates below 5 per cent, including many initiatives in pilot phases. These respondents include Hong Kong SAR at 1 per cent, Poland at less than 1 per cent, India at around 60,000 users, Brazil at 0.5 per cent, and the Republic of Korea at 690,000 website hits. The remainder of the respondents are working on mechanisms which allow them to measure the adoption rate or working on establishing electronic access to patient personal health information. These results are summarised in Figure 2.



Figure 2:Reported adoption rate metrics by survey respondent

3.4. OTHER INTERNATIONAL COMPARATIVE STUDIES ON THE STATE OF ACCESS

There are a variety of other studies that provide evidence about citizen access. Commonwealth Fund studies are notable for their international participation allowing for benchmarking. The studies are also repeated periodically to allow for some identification of trends over time.

The 2016 Commonwealth Fund International Survey of Adults provides a snapshot of reported citizen access at that point (see Figure 3 below) (1). Reported adoption was quite low at the time, with only the United States and France at above 20 per cent. Notably, in the four years between this Commonwealth Fund survey and the publication of this white paper, many countries included in both have launched or expanded major initiatives and are now reporting much higher adoption.

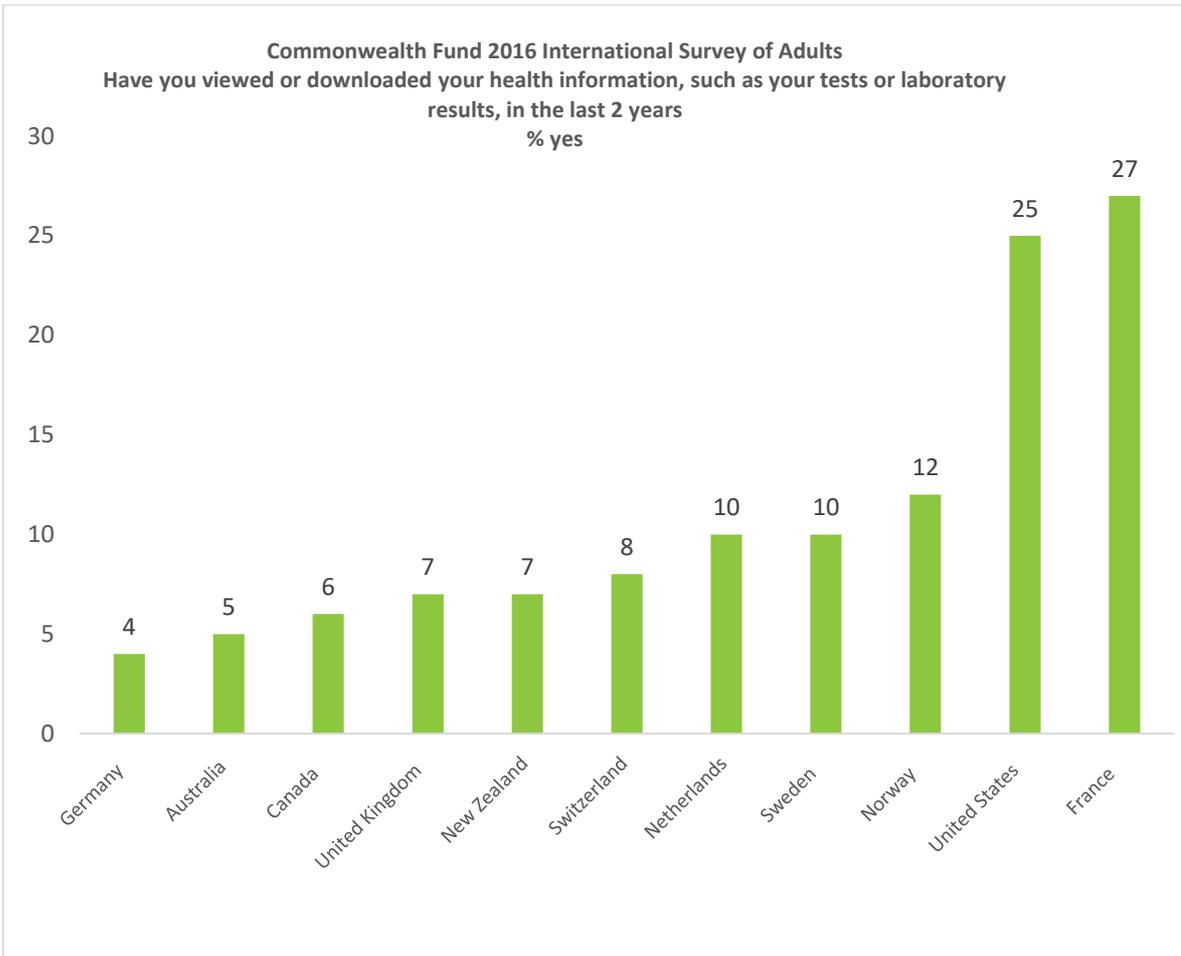


Figure 3: Reported access by people to their personal health information (Commonwealth Fund 2016 International Survey of Adults)

The 2019 Commonwealth Fund International Survey of Primary Care Physicians provides a more recent snapshot, with a focus on the offering of electronic access to personal health information by physician practices (see Figure 4 below) (2). In the majority of countries included the study, more than 20 per cent of physicians reported access by their patients to at least one type of information.

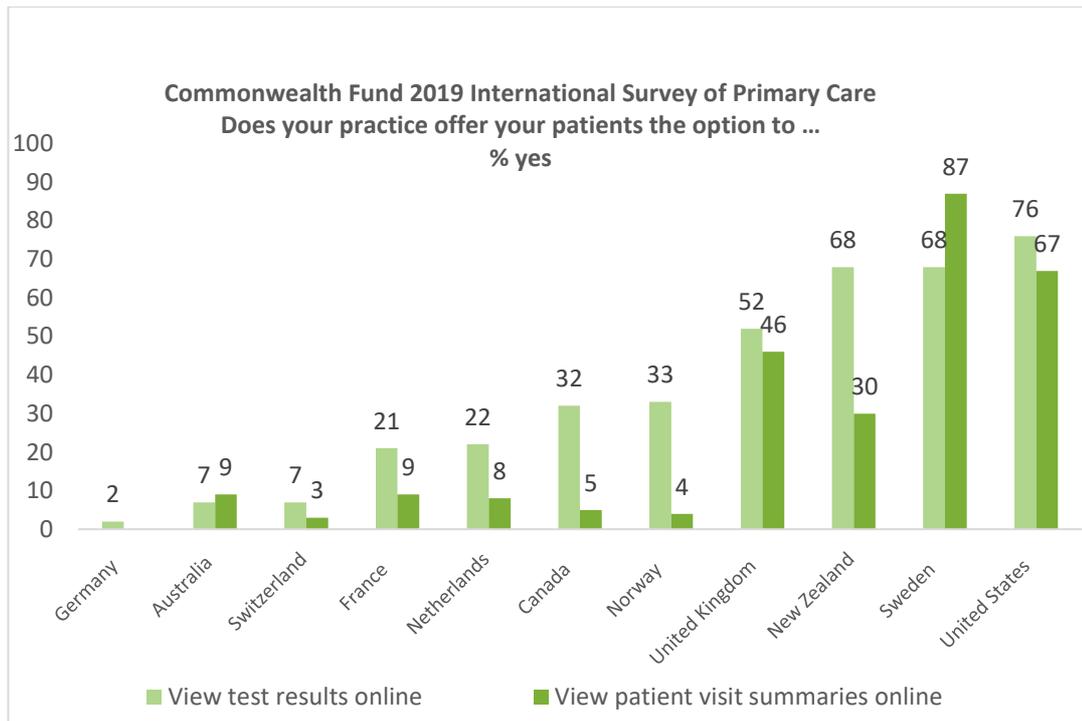


Figure 4: Offering of electronic access to personal health information by physician practices (Commonwealth Fund 2019 International Survey of Primary Care Physicians)

3.5. DEPLOYMENT OF CITIZEN ACCESS TO THEIR PERSONAL HEALTH INFORMATION

GDHP participants were asked to categorise their deployment approach for providing citizens with access to their personal health information. The three different approaches were:

1. A coordinated or national effort;
2. An institutional or provider-based effort; or
3. A blended approach.

The most commonly reported approach is a blended approach, six-in-ten respondents report taking this deployment approach. The remainder of respondents (four-in-ten) report a coordinated or national effort. This indicates that GDHP participants are recognising the value of scale and the need to integrate across the levels of government, organisations and sectors (see Figure 5 below).

Many participants with a blended approach are recognising the importance of addressing some issues at the national/coordinated level. There are many different approaches to national contribution or leadership, and some transferable lessons. Some have focused on legislation, policy and trust frameworks, with the United States, the United Kingdom, the Netherlands and Australia as leading examples. A number of countries are deploying nationwide technology solutions, with Estonia and Australia as leading examples. There are also examples of technology platforms that mediate access to personal health information, in an effort to increase availability to a range of services or applications that

can be more tailored to people's needs and wishes, with Hong Kong SAR, the United Kingdom and Canada offering examples.

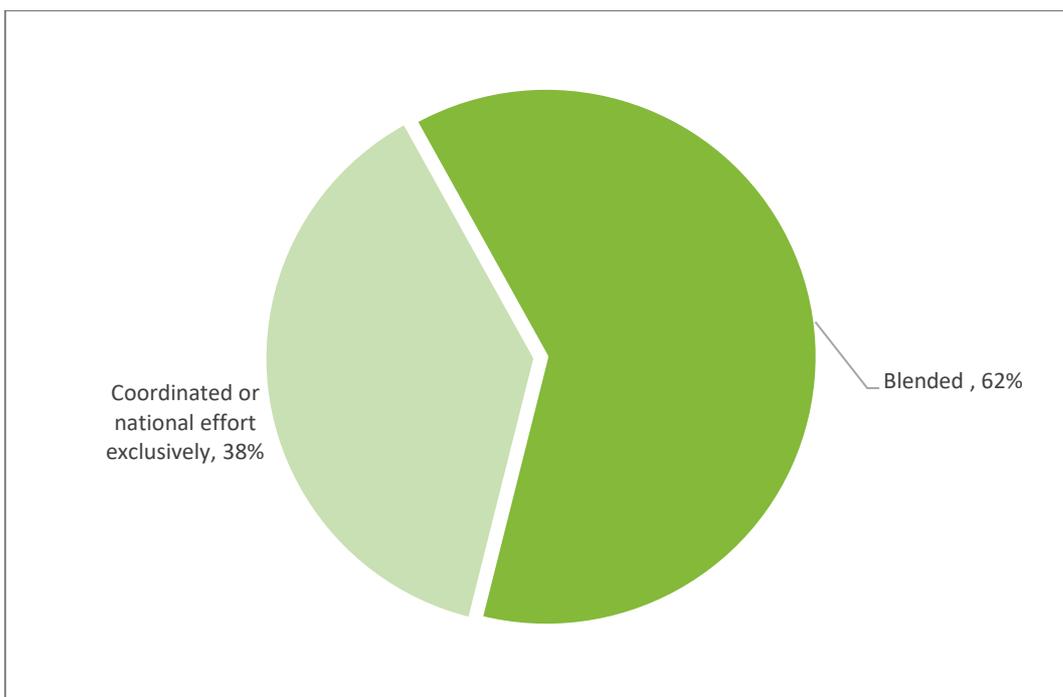


Figure 5: Percentage of respondents by deployment strategies for access to personal health information (N=21¹)

¹ Indonesia did not provide an answer to this question.

4 CASE STUDIES OF NATIONAL APPROACHES TO PROVIDING CITIZEN ACCESS

4.1. AUSTRALIA

Australia's digital health record system – My Health Record – is an online summary of a person's key health information. This system allows approved healthcare provider organisations (for example, doctors, hospitals physiotherapists and dieticians etc.) involved in the person's care to view their health information while also supporting a person's ability to access their own health information (test results, prescriptions) online.

The Australian Digital Health Agency (the Agency) has developed a nationally coordinated and multi-channelled approach to facilitate access to the My Health Record system for all its stakeholders. My Health Record can be accessed through the National Consumer Portal (NCP), through the MyGov platform, or through the four mobile apps available to all Australian citizens. Providers gain access through the National Provider Portal (NPP) or via their clinical information system.

National efforts to increase awareness and access to digital health tools like My Health Record have included the deployment of educational toolkits, advertising campaigns and incentives to healthcare providers, as well as legislative or regulatory changes that safeguard the use of digital health for both consumers and their healthcare providers. Future strategies must consider the complexities of the national policy across multiple jurisdictions and stakeholders as well as the cost-effectiveness of increasing digital health literacy within the context of digital citizenship as a whole.

4.1.1. Strategies to promote the adoption of personal health information

The key strategy to promote the uptake of the My Health Record system was the move from an opt-in to an opt-out system. The move to an opt-out system was informed by piloting and evaluation of an opt-out model in two regions. The opportunity started on 16 July 2018 and ended on 31 January 2019, following an extension to amend legislation to strengthen privacy protections in the My Health Records Act 2012.

The other important strategy was to provide a legislative framework for the My Health Record that clarified key accountabilities and roles and set up an access and control framework with appropriate penalties, prohibitions and protections.

Some institutional strategies may focus on specific digital health applications such as a localised electronic medical record (EMR) or telemedicine applications for a clinic or multiple groups of clinics. Other strategies that encourage direct consumer or patient involvement may be suitable for tailoring the system to meet the local needs of the consumer or patient. While these strategies are costly, they can be the most effective in terms of delivering the direct benefits of the digital health technology or service.

Previously, the Agency and digital health advocates at large, have focused on clinician perspectives of digital health, but efforts to embed consumer perspectives into the design of the national strategy on digital health are increasing.

Australia was successful in delivering My Health Record awareness to all Australian healthcare providers in readiness for the national opt-out system during 2018.

The Agency achieved this by collaborating with a range of delivery partners across Australia to reach all healthcare professionals including: primary health networks (PHNs); state and territory jurisdictions (public hospitals and associated organisations); private hospital organisations; and clinical and regulatory peak bodies including the Australian Health Practitioner Regulation Agency and Aboriginal Medical Services (National Aboriginal Community Controlled Health Organisation and affiliates). A range of communication approaches was used, including direct electronic communications, webinars, local awareness and education events, and online and written materials tailored for different clinical settings and healthcare provider groups.

Efforts to build trust among consumers need to expand if true and sustained behaviour change is to be achieved. Levels of trust can be increased by supporting consumers to develop their access and capacity to problem-solve with governments and clinicians through shared governance arrangements. Similar co-design processes are essential to guaranteeing the success of digital health engagement within consumer communities.

4.1.2. Trust framework

The Agency's community engagement program focuses on improving digital inclusion for vulnerable and hard-to-reach consumer groups across rural, regional and remote Australia. These consumers include Aboriginal and Torres Strait Islander People, refugees and recent migrants, youth (14–25 years of age), older Australians, and caregivers of children. A key focus for the Agency is to work with these specific community groups to understand their needs and capacity to achieve better outcomes through the effective use of digital health technologies.

In late 2018 through to June 2019, the Agency undertook several consultation forums and commissioned engagement activities with consumers from these groups to understand their needs. Through these engagements, it became evident that more targeted communication, engagement and education activities is required to address the specific needs of consumers in areas such as informed consent, privacy, security and general awareness. Consumers identified that a stronger emphasis by the Agency on digital health literacy, participative engagement, and involving them in the design of materials would strengthen the Agency's collaboration and trust framework with consumers. This approach will, in turn, empower consumers to be more engaged in their own health care and drive more meaningful use of My Health Record including the confidence to request that clinicians upload information such as shared health summary, discharge summary, pathology and diagnostic imaging test results.

Examples of the projects currently underway to consolidate and build trust with consumers include:

- Working with key partners to deliver a digital health literacy program across Australian communities including education curriculum for youth in schools;
- Developing a comprehensive refugee and recent migrant work program in collaboration with consumers and clinicians; and
- Putting in place a targeted program 'Communities of Excellence' to better connect the needs of consumers with clinicians in rural, remote and regional communities.

In addition to consumer-specific programs, a Consumer Advisory Committee provides on the suitability of the community engagement programs specifically for vulnerable and hard-to-reach consumers.

Moving forward, Australia should concentrate national efforts on developing a more comprehensive understanding of the consumer or citizen's perspectives about digital health.

4.2. CANADA

In Canada's provincially administered health system, there is a blend of channels for Canadians to access their health information. Through these, many Canadians could access their health information, and 20 per cent say they have. Province wide portals offer citizens access to their key health information in Quebec, Alberta and Saskatchewan, representing almost four in ten Canadians. Many citizens in Ontario and British Columbia (where five in ten Canadians live) can access their lab results through lab service providers. Some leading hospitals and clinics across Canada are also offering access. Canadians are already seeing value, but there is much room for growth.

Canada Health Infoway, with funding from Health Canada, has a program called ACCESS Health that provides Canadians with access to their personal health information and to digitally enabled health services. The program aims to provide Canadians with a greater ability to manage care, more convenience, and increased control over personal health information. This digital ecosystem will allow Canadians to:

- View personal health information online;
- Share health information with others (for example, friends/family, healthcare providers); and
- Use self-management applications.

Central to this work is the "Trust Framework" that allows health information systems to connect and share in a way that meets the needs and expectations of Canadians. It includes rules for operation and participation, such as policies and agreements around data sharing and how users can control their health information. Individuals will be able to control access to their health information with the potential of enabling/disabling it for various mobile apps/website applications.

4.3. ESTONIA

Estonia is widely recognised as the champion in Europe in the online provision of public services. Estonia government information system currently consist of 642 information systems in total offering 4,196 services. The three pillars that maintain their durable e-society include: 1) an identity code for all citizens; 2) authentication, digital signature, and personalised encryption using an electronic ID card; and 3) a system that permit the use and meaning utility of data that minimises storage or transmission of data unnecessarily.

4.3.1. Drivers behind citizen access to electronic personal health information in Estonia

The architecture of the Estonia e-state

Over the past few decades, Estonia has developed itself into a digital state where a central gateway provides citizens with access to all national e-services. Part of that architecture is Estonia's electronic patient portal (i.e. Estonia.ee). Estonian citizens can securely log in to the portal via a single citizen ID-card which provides them access to all government-related services using the single e-state portal. Usage of the portal is high as the incentive for people to access this portal is not just health-related, for example citizens can also do their tax online, check for kindergarten waitlists, as well as access their personal health information. Having access to the state portal has familiarised Estonians with interacting with the state using the online platform, thus making the transition from paper to digital personal health information sharing much easier.

The inclusion of service within the portal

Estonia believes that the real value of patient portals lies with the services people can access from the portal. There was a huge spike in access to the portal when Estonia included information regarding the health insurance fund (that is, how much medical services actually cost). Citizens were interested in checking how much services cost even though they might not have to pay out-of-pocket for those services. Another example that spiked portal access was adding the health certificate on the portal. This is a questionnaire that citizens need to complete via the patient portal for employment purposes. Estonia recently added an e-booking service for specialist and emergency services to the health portal which allows citizens to view all available specialist/emergency departments and their wait times across the country. This was added to solve a triaging issue in Estonia. These use cases are good demonstrations that access to patient portals can be increased by adding essential services or information.

User experience and usability

Estonia is currently putting in efforts to make the health portal more relevant and user-friendly to further boost access. This includes a complete overhaul of the look and feel of the portal and may also include updates to the types of information/services that will be included on the portal.

Citizen engagement efforts

Estonia does not currently have a very strong patient representative in health system-level decision-making. Estonia has traditionally designed its patient portals based on health system needs and acted based on top-down approaches. People are consulted on certain projects, for example the recent initiatives on making the patient portal a consent platform.

The main factors that affect the design of the patient portal and the types of services/information it includes has been to solve emerging health system-level issues or to achieve certain health system reforms. (see strategic goals:

https://www.sm.ee/sites/default/files/content-editors/eesmargid_ja_tegevused/Eesti_e_tervise_strateegia/e-tervise_strateegia_2020.pdf).

By and large, Estonia has followed a top-down approach to health system-level decision-making as resources are limited. Clinicians and hospitals; however, do voice their opinions through unions. Union representatives approach the e-health agency and, subsequently, a committee may be created to act on their concerns.

Future plans to increase use and value of access to personal health information

Estonia has always designed and perfected its patient portal based on the underlying theory that use will always depend on what kind of services are provided through the patient portal. Estonia's approach has been to identify urgent health system reform needs (for example, triaging of specialist care) and address the need using the patient portal as a platform (for example, incorporating e-booking services on the portal). This has worked well for Estonia with an approximately 50 per cent access rate by citizens. Another step in the future is to help people better use their health information via data visualisation. Using the state-run health portal as the architecture backbone, Estonia plans to use the patient portal as a consent platform so that patients can have control over their data and decide to whom they want to provide access and how they can best use their data.

Estonia is using vaccination as a use case for patients to give consent to allow third-party vendors to use this data to support patients by creating a vaccination reminder app. Patients will have control over their data via the portal (for example, to give consent or not). Once they give consent, app developers will have their vaccination data to create personalised reminders for future vaccinations. Another project on the horizon is a personalised medicine project where patients can provide consent for their genetic data – which has been gathered and centralised onto the patient portal – to be used for risk assessment (via primary physicians or potential vendors). The patient portal is already functioning as a consent platform where patients can choose to close their portal so that their data is sealed for usage or provide consent on organ donations. The development of the vaccination and personalised medicine use cases will take this one step further.

4.4. THE NETHERLANDS

The Netherlands currently has a national program called MedMij that will be pivotal in providing patients with access to and use of their health data. MedMij (Dutch for MedicalMe and a play on the words With Me) is a national coalition led by the Patient Federation – which represents over 150 patient organisations – with payers (health insurance), providers (academic and general hospitals, primary care, GPs, social care, pharmacy, physiotherapy, mental health care, nurses, etc), and government (national and local), all working together to give patients control over their own data. MedMij is the standard in the Netherlands for the secure exchange of health data between care users and care providers. Anyone that meets MedMij's criteria may use the MedMij label.

MedMij isn't a system; it is a trust framework with governance rules, roles for participants, certification and standards. It doesn't deal with making personal health data available to patients, but with what happens when patients/citizens/consumers get their data – how do they collect all their data in one place, store it safely, share it securely, and control where, how, by whom and why their data is used by others. Currently more than 80 service providers are in the process of being certified, with the first 15 having gone through this process successfully.

MedMij's core task is to facilitate the digital exchange of health data between residents of the Netherlands and their caregivers. MedMij is also creating confidence that this is done in a secure, affordable, future-proof and user-friendly way. One of the ways MedMij is doing this is by designing a solid framework. The agreements contained in the framework are essential to create the trusted environment in which patients and caregivers feel secure to exchange health data and thus get the system off the ground. This trust is symbolised by the MedMij label that indicates that a product or service is compliant with the MedMij Framework. A report prepared by Gupta Strategists on the

costs and benefits of personal health environments ([in Dutch, pdf](#))² estimated the costs of developing and implementing personal health environments to be about €500 million over the next 10 years, while the benefits are over €3 billion in shared savings at the governmental and healthcare provider level.

The MedMij project developed the trust framework in a public-private partnership financed by the Ministry of Health and the healthcare insurers. This is being done incrementally and with open consultations at every step. The whole framework has been validated by the members of the National Health Information Council, where all stakeholders are represented. No special legislation is necessary to provide legal grounds for the framework.

The MedMij framework has two roles: patient-facing (personal health data) service providers and healthcare provider-facing (PHD) service providers. Each role provides communication and value-added services for their client, based on Fast Healthcare Interoperability Resources (FHIR)-based open application programming interfaces (APIs). For instance, one service provider collects health data from a social care provider's electronic health records and builds self-care and blended-care programs using that data, like an online depression treatment for youth. This service provider is certified for both the patient and the healthcare provider-facing roles.

MedMij is being implemented in controlled incremental steps. It requires health data to be available from healthcare providers in a structured way. A large government incentive scheme to make health data exchangeable in a standardised manner has the MedMij requirements as one of the criteria for receiving subsidies. This has every hospital, most GP practices, clinics, social care institutions, pharmacies and laboratories implementing MedMij endpoints. The Ministry of Health is investing almost €500 million in this scheme.

For a controlled rollout among patients and citizens, the Ministry of Health subsidises every patient who uses a MedMij certified PHD provider, so they can use it for free. This prevents selection of digital health services based on income. In time, there will be a structural financial solution for PHD providers, to keep it free for patients.

MedMij is still young, the controlled roll-out of the very first PHD service providers started in 2019, after two years of developing the trust framework, standards and instruments. The use cases on which providers can be certified are still limited. The next steps will include developing new use cases and learning from the feedback from real life use and experience.

4.5. SWEDEN

Sweden has been a leader in citizen engagement with digital health. By January 2019, close to 3 million first-time users (out of a total of 10 million citizens) had logged on to the service providing people access to their personal health information. Every month one million unique users log on.

Some services, such as prescription information, are national, while services for Patient Accessible Electronic Health Records (PAEHR) vary between the regions. The regions are

² <https://www.medmij.nl/wp-content/uploads/2017/07/Rapport-Gupta-Kosten-batenanalyse-persoonlijke-gezondheidsomgevingen.pdf>

responsible for providing health care and they offer access to the information in the electronic healthcare records.

The PAEHR services are provided by SALAR (Swedish Association of Local Authorities and Regions) through their service provider Inera. Sweden has many legacy software systems with associated interoperability issues, which are in the process of being updated. Many regions are in the process of procuring new systems for electronic health records and this will give patients access to their own information through the portal at Inera.

When the first PAEHR service was introduced, it was through the work of a very dedicated IT strategist in the Uppsala region. His vision was supported by the regional leadership and implemented in a project, Sustain, funded by the European Commission. Other regions followed and today all regions offer at least a minimum of information to their citizens.

The portal, 1177 - a name that was originally a phone number to call for medical advice – is being used by patients to access information in their electronic health records and also used for healthcare advice in general. The information on the site, and the advice given by certified healthcare professionals, is quality assured and 1177 as a trademark is well known and respected.

Swedish citizens have a personal number that uniquely identifies them. The personal number is used in all public records. It also provides the basis for the eID which makes secure identification possible. This mutual use of the personal number ensures that the right information is accessed by the right person.

Developments in eHealth are proceeding quickly and there is a high demand from patients to access their information on different platforms or devices. Visits to Digital Doctors have become a great success in Sweden and several regions are introducing their own services.

The National Board of Health and Welfare was given a government assignment in 2018 to produce recommendations for the type of care and treatment that is suitable and not suitable for management through digital healthcare services. This assignment resulted in a number of overall principles:

- Existing regulations or current knowledge management do not require a physical meeting.
- The digital service is adapted to the individual patient's needs and conditions for using the service.
- The healthcare provider has access to adequate information about the patient's health and medical history in order to provide a good and safe care.
- Necessary follow-up and coordination with other actors are possible.

Evidence suggests that these services are valued by people. According to a survey done 2017, five years after the introduction of access to electronic health record information in the region of Uppsala, the positive effects for patients are:

- Access to test results is the most important function for patients.
- Patients use the online portal primarily to get an overview of their health and contact with the healthcare system, and to follow up after a visit.

- Patients are very positive about the opportunities for reform that the system provides.

The opinions among the medical professions have developed towards greater acceptance. Initially, a common opinion was that the medical record was the doctors' own work tool and of no use for the patient. There was also a fear that the patient would not understand the contents of it. Over time doctors and nurses have come to appreciate the opportunities for interaction with patients that digitisation provides.

4.6. UNITED KINGDOM

Within England, the National Health Service (NHS) has provided patients with access to their GP records for a number of years, with the number of registered users at 15 million in 2018. In 2019, the NHS launched the NHS App; this app has set a new baseline for the way the population is able to access their GP records. This was designed in line with the TechVision, with user-centred design and inclusive design at its core. Having a nationally developed app has supported real-time data collection, which means the NHS is better able to understand how the data is being used. Therefore, while the downloads are small, in line with the delivery approach with a public beta to make sure that the service "gets this right" for people, it allows real-time monitoring of: the number of times records have been viewed; the number of GP appointments booked and cancelled; and the number of times prescriptions have been ordered. This level of analytics is unprecedented in terms of understanding activity within the system, even as a proxy measure, allowing for demographic considerations.

The next challenge to overcome is how to stitch together the data sets that sit outside of primary care. There are various schemes underway to support this, including global digital exemplar programs to support with the digitisation of acute and community settings, and local health and care records that enable localities to work together to share data across care settings. Some national interoperability features as enabled via the 'Spine', such as the personal demographic service (PDS) and event management capability, also supports data sharing in specific care settings such as child health and maternity. The aim of working to digitally transform the NHS will help to increase the number of records that are available digitally, which will ultimately support access by people to their records.

The NHSX citizen mission focuses on supporting people to have access to their records in order to support with shared decision-making, patient activation and choice. Work is progressing to develop a series of components for developers and localities to make use of in order to deliver on these objectives:

- NHS Login is an identification component that is available for developers to test in a sandbox, before being assured and deploying to their device, as a means to authenticate a person using their NHS ID number.
- NHS.UK is one of the world's most visited health information resources with more than 40 million hits per month; a content modularisation piece of work is underway to enable developers to access the world-class content and use this to support people with reminders and behavioural nudges.
- The events management service, is also supporting the delivery of specific bits of health information to both professional and people's records with a view to enabling people to enter data into their records directly in the next phases.

A digital inclusion guide has been produced for health and social care. It sets out what is meant by digital inclusion, why it matters, how it can be supported, how to design services for inclusion and a number of case studies. The document can be found here :

<http://digital.nhs.uk/binaries/content/assets/website-assets/corporate-information/inclusion-guide-documents/downloadable-digital-inclusion-guide.pdf>

There are a number of initiatives underway to support patient access to information. The United Kingdom has good visibility on GP data but other areas are mixed. The NHS App provides patients with access to their GP record as well as a number of services such as appointment booking and repeat prescription ordering.

The Local Health and Care Record program which has a number of exemplar sites has a requirement for each site to support access to a personal health record which is populated with information from across a number of settings of care and also allows patients to add their own information.

We are working through child health and maternity to make the data available, in particular for maternity through the use of an electronic red book – our record of pregnancy.

4.7. OTHER PARTICIPANTS

A number of other participants not highlighted in the case studies are also working with unique strategies to deploy arrangements for their people to access their personal health information. The following sections describe each briefly.

4.7.1. Austria

At present, Austria's ELGA portal is broadly deployed. The majority of services are coordinated on a national basis, but services which are not intended to become nationwide, remain on an institutional/provider basis. The further extension of people's access to their health information is a priority. In every ELGA use-case, the citizen is at the centre, and thus each application's data will, in principle, be made accessible on the patient's portal. In particular, the upcoming "e-Immunization" application is expected to deliver a large direct benefit to people, by replacing the paper-based immunisation record and increase patient's safety by providing immunisation plans and procedures.

4.7.2. Japan

Japan currently maintains a national immunisation record maintained by local governments which people can be review on the national site. Japan is also currently carrying out projects that aim to provide people with access to other sorts of information through the national site after the 2020 financial year. Those information categories include paediatric check-up information held by local governments, and specific medical check-up information and medication information held by health insurers.

4.7.3. The Kingdom of Saudi Arabia

Citizen access to personal health information in the Kingdom of Saudi Arabia can be categorised in two major types:

1. A nationally, coordinated (across all government entities delivering healthcare including Ministry of Health, defense and private hospitals). Client/patient portal view of the Kingdom of Saudi Arabia's universal health record which is currently being developed and estimated to be live by December 2020. This will include access to:
 - a. Provider entered information
 - b. Client/patient entered information such as a medical report or allergies
2. Personal health information (entered by the citizen) supports 6 specific models of care. This is currently being developed by the Ministry of Health only for 6 conditions. It is anticipated that this will be scaled after the pilots are completed.

It is anticipated that this will be scaled after the pilots are completed and the goal is to reach 40 per cent adoption rate by 2020.

4.7.4. Poland

Poland has designed the Patient Online Account user interface for the Health Care IT Systems Center (CSIOZ) unit of the Ministry of Health. The Patient Online Account, accessible via pacjent.gov.pl, will serve as an online health card for each citizen of Poland. All information about doctor visits, prescriptions, drugs prescribed and bought, referrals, and completed tests, will be gradually brought online. Some of the features referred to above are already available on the website. The Patient Online Account service is a gigantic IT undertaking. It will be built in stages – currently development work is planned to last until 2020.

4.7.5. Portugal

The National Strategy for Health Information Ecosystem 2020 (ENESIS 2020), approved in 2016, is a strategic initiative that provides a common vision to health IT systems that allows the steering of strategy and initiatives of several stakeholders of the healthcare IT ecosystem in Portugal, and acts as a reference for good practices. The strategy was designed for healthcare professionals and is to be citizen-centred. The initiative aims to provide engagements that are responsible and transparent for all the players in the healthcare system, allowing the use of multiple platforms and digital services. The results point to:

- Better sharing of information;
- Simplifying processes and documents such as electronic prescription of medicine, associated death certificate processes and medical leave;
- Improving the availability of data and services through Health Data Platform and associated portals; and
- Facilitating better public access to open data on the National Health Service Portal and governmental Data Portal.

4.7.6. The Republic of Korea

“Health IN” is a website providing personal health information in the Republic of Korea and managed by the National Health Insurance Service (NHIS) as a single payer.

4.7.7. Singapore

Singapore is deploying a digital health app to provide citizens access to their information. It has been downloaded by 580,000 people to date. A feature, available on a digital health app, is currently on trial in a selected group of patients to enable patients to see their doctor’s advice, test results and medicines prescribed. This is an initiative to transform the outpatient experience during visits to specialist outpatient clinic (SOCs) to:

- Improve accessibility for patients to make their appointments from polyclinics to specialist outpatient clinics;
- Improve the experience of patients on-site; and
- Enable patient self-management at home by providing them with a home monitoring platform.

4.7.8. Switzerland

The Electronic Patient Record (EPR) will be available in every region of Switzerland by Spring 2020. It is a personal collection of treatment-related documents accessible to patients and their healthcare professionals. Whereas inpatient healthcare providers, including hospitals are obliged to implement the EPR, the outpatient sector and citizens are free to opt in. A national law on the EPR and a certification process ensure the interoperability and the safety and security level of the about ten different EPR providers (see: www.patientrecord.ch).

4.7.9. United States

The discussion about citizen access to personal health information in the United States has shifted dramatically from just over a decade ago. During the nascence of electronic medical records, the argument had often centered around justifying their use over traditional paper record-keeping strategies. At the time, many were concerned that storing patient-specific information on digital devices would lead to inappropriate release and use of such data. A 1997 publication of the National Research Council of the National Academy of Sciences in Washington, D.C. addressed these issues in great detail (see: <http://pdfs.semanticscholar.org/d46d/1c4f5871d3c915d220c7e0350c2c7054583b.pdf>).

In addition, integrating computer use with the workflow of clinicians was another major challenge (and remains a challenge to a certain degree). Fast forward to today and there is a different set of challenges such as system interoperability, data security, and ensuring physicians have horizontal access to all types of information technology. The debate has moved away from whether patients should have access to their personal health information to a discussion about how best to provide equal access for all patients to their information in a safe and secure manner.

Many hospitals and physicians possess capabilities that enable patients to view and download their health information. However, additional steps are needed to make health information more accessible and useful to individuals. A majority of individuals have smartphones and use applications (apps) to help them manage various tasks. The 21st Century Cures Act emphasizes the importance of making patient health information more easily accessible and the need for greater education regarding patients' rights to access their health information.

The Health Information Trends Survey (HINTS), a nationally representative survey, assessed individuals' access, viewing and use of their online medical records, and the use of smartphone health apps and other electronic devices in 2017 and 2018.

The percentage of individuals who were offered access to their online medical record did not change between 2017 (52%) and 2018 (51%). In 2018, about 3 in 10 individuals were offered access to their online medical record and viewed their record at least once within the past year. Individuals' rates of being offered access and viewing their online medical records at least once in the past year varied by their health care use, socio-demographic characteristics, Internet access and use, and health. Among individuals who viewed their online medical record at least once in the past year, the percentage that downloaded their health information increased by about one-third between 2017 and 2018. In 2018, half of smartphone or tablet owners had health or wellness apps which were commonly used to track progress towards a health-related goal (75%). See: <https://www.healthit.gov/sites/default/files/page/2019-05/Trends-in-Individuals-Access-Viewing-and-Use-of-Online-Medical-Records-and-Other-Technology-for-Health-Needs-2017-2018.pdf> .

4.7.10. Uruguay

Uruguay is currently developing a portal in which every citizen will have access to their clinical information registered in the national digital healthcare platform. The portal is anticipated to be live by the end of 2019. At present, a few providers in Uruguay have portals to allow their clients to access some portion of all of their clinical information. In the future, these provider portals will coexist with the national one.

5 RESULTS: ANTICIPATED AND REALISED IMPACTS OF CITIZEN ACCESS

5.1. DRIVERS OF THE GLOBAL SHIFT

Improving patient engagement and empowerment was by far the most frequently reported driver for providing people with access to their personal health information, whereas avoiding unnecessary visits (cost-savings) is the least mentioned major driver for investment (see Figure 6).

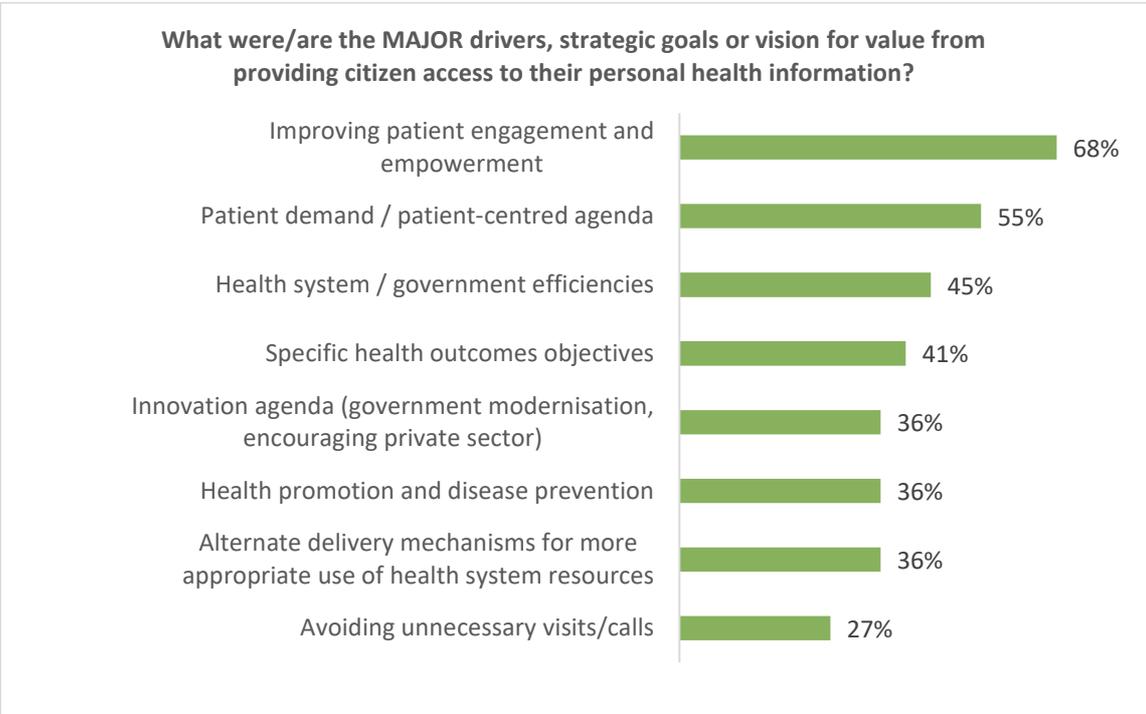


Figure 6: Drivers for providing people access to their personal health information (N=22)

A number of countries – such as Estonia, Portugal, Uruguay and the Netherlands – focused on the philosophy of citizen ownership of data and centrality. One key informant described access by people to their information as an opportunity to address the power imbalance that exists between patients and clinicians. A number of countries that approach it as “the right thing to do” have focused on liberating the data for citizen as the primary objective, with the understanding that empowering patients is the starting point for a range of improvements. In other countries, access to information for patients is more focused on specific use cases or clinical objectives, such as post discharge care or management of chronic disease.

Other drivers for providing people with access to their personal health information include: improving the quality of care and patient experience (for example, reduction in adverse events, better coordination of care, reduced wait times, improved patient outcomes); reduction in health costs (for example, reduced duplicate testing, better self-

management by patients); providing equity in access to clinical information; and ensuring patients their constitutional rights.

5.2. IMPACT OF ACCESS TO PERSONAL HEALTH INFORMATION

Improvements in patient engagement and empowerment were the most frequently mentioned impact (see Figure 7 below). This theme was also the most frequent driver for providing people with access to their personal health information.

Other notable positive impacts mentioned by jurisdictions were: increased patient satisfaction; increased patient empowerment; and improved efficiencies (for example, early diagnosis of chronic diseases, and reducing unnecessary visits).

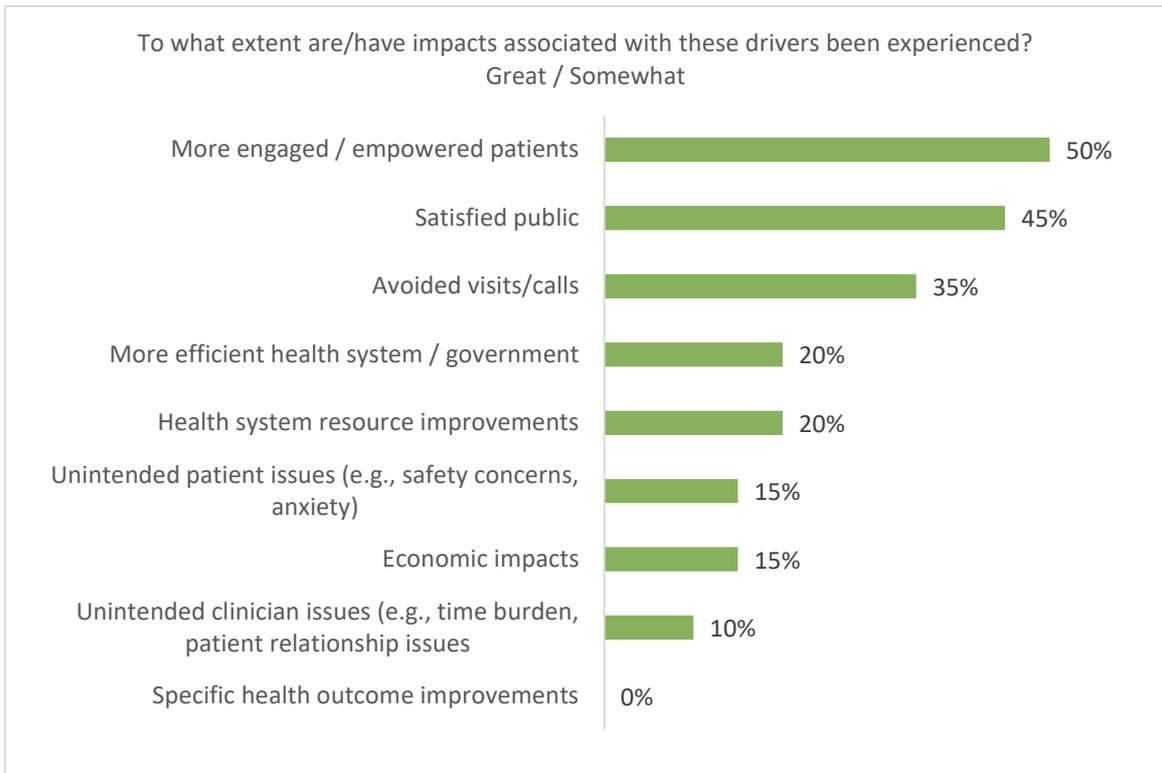


Figure 7: Impacts of providing people access to their PHI. (N=22)

Many jurisdictions did not respond about the negative impacts. Of those that did, responses include miscommunication between patients and health professionals, technological knowledge barriers among seniors, and the potential for errors during implementation and initial stages of use.

5.3. LIMITED EVIDENCE STILL AN ISSUE IN MANY COUNTRIES

Jurisdictions mentioned a number of challenges in relation to their ability to conduct evaluations to accurately assess the impacts of these drivers. The disparities that exist between what consumers perceive to be a benefit of digital health, and what governments perceive to be a benefit of digital health could lead to misleading evaluative

outcomes. Confounding factors were also mentioned – such as other initiatives that are implemented in parallel with the deployment of the electronic health records – making attributing outcomes challenging. It is difficult to measure the specific benefits that are derived from access to personal health information alone. The benefits to the patient and the health system might be directly or indirectly correlated with other functions enabled in parallel with access to personal health information.

5.4. EVIDENCE HAS GROWN IN THE BROADER LITERATURE

The evidence base about the impacts of people’s access to their personal health information has grown dramatically in the last decade, but notable gaps remain.

One recent systematic review found “Patient portals are increasingly available, but their impact on health outcomes has yet to be established. Previous systematic reviews found positive effects on patient engagement and satisfaction, but evidence on the effect of patient portal use on care processes and health outcomes is conflicting.”(3)

The evidence around patient engagement and satisfaction are consistent with country and territory responses, which reflect these as the most commonly experienced impacts. One systematic review found that “in general, there was a high satisfaction and acceptance by users of patient portals”.(4)

An analysis revealed that other impacts were experienced by one out of three respondent countries. One example of this includes “avoided visits/calls”. While there is less evidence on this issue, there is some basis in the literature. One systematic review reported: “There was some evidence that patient portals impact on costs or utilisation, including a decrease in office visits. However, there were also some studies which found a higher health resource use.”(4)

The relationship between access to health information and outcomes remains complex. Focused effort is required to achieve clinical outcomes, and the role of access to information as part of a chain of events necessary. For example, for patients to improve self-management of chronic disease highly effective interventions combine access to information with education, counselling and/or prompting.

5.5. MEASUREMENT OF CITIZEN ACCESS IMPACTS IN CANADA

Canada Health Infoway has applied a structured approach to measuring the impacts of citizen access, including developing indicators and measurement priorities (starting in 2010), annual measurement of adoption (starting in 2010), collaborating on and funding of primary research and project evaluations (starting in 2013) and modelling potential adoption and benefits (starting in 2015).

Some key products of this approach include:

- Direct lab study demonstrated that patients with access to lab results are more likely to receive their results, no more anxious, and are less likely require a visit: www.jmir.org/2015/8/e191/ and www.infoway-inforoute.ca/en/component/edocman/2775-impacts-of-direct-patient-access-to-laboratory-results-final-report/view-document?Itemid=0
- Portal project evaluations have largely demonstrated the patients are satisfied, more empowered and often avoid unnecessary visits to their doctor : www.infoway-

inforoute.ca/en/resource-centre/search-by-topic/benefits-evaluation/?q=portal¶ms=all!all!relevance!10881!0!true

- Canadians have strong interest in access to their information and e-services, and trending demonstrates increases in adoption as reported by citizens: <https://inforoute.ca/en/component/edocman/3786-access-to-digital-health-services-2019-survey-of-canadians-summary-report/view-document?Itemid=101>
- Valuing Canadians’ Secure Access to Information demonstrated significant potential value for Canadians and the health system with citizen access: www.jmir.org/2019/6/e12277/
- Videos provide patient and provider stories to illustrate the value so far: www.youtube.com/channel/UCMhF9j2YZQqTI-wHU51MI5Q

5.6. MEASUREMENT OF CITIZEN ACCESS IMPACTS IN THE UNITED KINGDOM

The United Kingdom has estimated the benefits associated with citizen access to information in the following categories.

5.6.1. Administration – photocopying and postage of subject access requests.

A review was carried out across a number of London areas that are part of the North London Care Information Exchange to understand the cost savings in sending letters and responding to subject access requests (a part of the Data Protection Act in the UK). These can be summarised as follows.

Cost	Y1	Y2	Y3	3Y Total
Total	£367,362	£501,417	£635,473	£1,504,252

5.6.2. Administration – printing and postage of clinic outcome letters

Postage costs could be saved where patients opt to receive clinic outcome letters through the Care Information Exchange (CIE). Evidence since the introduction of emailed appointment letters suggests that at least 20 per cent of patients prefer to receive letters electronically.

An acute trust receiving over 5,500 requests each month would save over £80,000 per year.

5.6.3. Administration – reduced booking admin and support costs

Work by University Hospitals Southampton found that admin and support staff currently help patients to use appointment booking services. Patients will be able to do this directly themselves using My Medical Record (MyMR). This will free staff to work more on MyMR.

Staff using the existing UHS patient administration system currently take:

- 43 seconds to cancel an appointment
- 143 seconds to rebook an appointment
- 52 seconds to attend an appointment

Around 8 per cent of outpatient appointments are not attended.

MyMR usage is planned to reach 100,000 users by the end of 2019.

That means an estimated non-cash releasing benefits saving over 5 years of £565,000. This assumes a 20 per cent reduction in face-to-face attendances that need admin team support.

5.6.4. Administration – reduction in paper and postage costs

University Hospitals Southampton are working to save further money on paper letters and stamps by sending letters electronically. Patients using MyMR can sign up to receive these paper-free communications. Savings based on an estimate of two letters per appointment are:

- An ambitious saving over 5 years of £891,058.07
- A moderate saving over 5 years of £702,637.82
- A conservative saving over 5 years of £376,709.38

5.6.5. Admission savings

East Surrey Hospital has introduced a personal health record that allows its inflammatory bowel disease service to save approximately £232,320 a year, by avoiding hospital admissions and appointments.

5.6.6. Nursing time saved

Nurses can save time during face-to-face pre-operative assessments, as patients can use MyMR to provide some information beforehand. This will also provide more accurate data for patient administration systems.

5.6.7. Online savings

Costs of holding physical outpatient appointments can be cut by holding them online instead. The cost of providing a face-to-face follow-up appointment in urology for example is £84.

This is a loss-making service for University Hospitals Southampton, as the tariffs were reduced to £74 for 2019/20.

This cost is made up of:

- Admin support time, including reception, house-keeping services time, facilities management and clinical support;
- Admin to book an appointment;
- Car parking maintenance;
- Nurses' and consultants' time; and
- Space in clinic.

Based on an assumption of a 20 per cent reduction in the number of physical appointments, there would be an estimated cash saving of £7,488,000 across 5 years, if the same cash saving profile is assumed across all services, and if it achieves a 20 per cent saving in the number of outpatients.

University Hospitals Southampton have negotiated a tariff with their Clinical Commissioning Groups (CCGs) for their My Medical Record outpatient replacement reviews. This provides additional income to the trust.

CCGs would save £14,911,889 over five years if they adopt the same approach of using MyMR that the Prostate Cancer Service uses for its service, based on the current tariff and cost savings achieved. This is calculated using a 20 per cent saving on outpatient appointments.

University Hospitals Southampton has released cash savings of £40,000 for the trust in the financial year 2018/19 and £31,000 for the CCGs.

6 DISCUSSION: THE FUTURE OF CITIZEN ACCESS AND EMERGING AREAS FOR INVESTIGATION

6.1. RAPID EXPANSION TO AND INTEGRATION WITH BROADER SERVICES AND APPLICATIONS

The trajectory of access initiatives commonly includes growing functionality above and beyond viewing personal health information, as evidenced by the country and territory reports and case studies included above. The case study below from the Hong Kong SAR provides one example.

6.1.1. Case Study | Hong Kong SAR

Hong Kong's Hospital Authority is responsible for managing Hong Kong's public hospitals services.

The Hospital Authority is a "people first" organisation whose vision is to help people stay healthy. The Hong Kong SAR Government's policy is that "no one should be prevented, through lack of means, from obtaining adequate medical treatment".

One of the five portfolios under the Hospital Authority's IT 5-year strategic portfolio is enhanced patient experience and outcome, which focuses on new patient-centric service models with disruptive technology.

Since 2011, the Hospital Authority has developed a variety of patient apps to address specific patient needs. Pilot programs to give patients access to their health information, including test results, medications, hospital summaries, etc., have also been launched. To make all these tools and services available for the entire population, the Hospital Authority is deploying HA Go, a unified patient app platform.

In the words of the Chief Medical Informatics Officer, Dr NT Cheung, "we are building a single patient app that we call HA Go – with significant benefits over the previous collection of discrete apps. First of all, it's a one-stop shop. You download a single app, and register just once and all the apps will know who you are. Secondly, it functions as a conduit – it's not just a collection of little apps, it is a framework for allowing your health care to extend out from the hospital or clinic to the rest of your life with a consistent approach to user experience, patient privacy and data integration with the electronic medical record."

The HA Go app platform has a modular design consisting of 'mini apps' which can either be downloaded by the patient or prescribed by their clinician. For instance, diabetic care will be a mini app which will be prescribed and pushed to the phones of diabetic patients who need it.

It will be the change agent to modernise healthcare delivery so that patients can take a more active role in their own care and will help to complete various healthcare service loops.

6.2. EMERGING CHALLENGES AND AREAS FOR FURTHER INVESTIGATION

A number of emerging challenges were identified in country and territory submissions. Commonly identified challenges included:

- Data quality issues
- Security and data privacy issues
- Identity and consent management
- Clinician engagement, roles and compensations
- Updating regulations which weren't designed with citizens in mind
- Public digital health and health information literacy
- Limited evidence of impacts

Some of these – as well as some other opportunities – were identified as areas for further investigation by the working group:

1. Targeted use cases

Sharing or potentially developing some of the most important use cases for citizen access could help participants to maximise value (for example, avoiding unnecessary visits) and minimise negative impacts (for example, anxiety around sensitive test results).

2. Engaging clinicians

Clinician concern about negative impacts was identified as an issue, as was the opportunity for clinician encouragement to drive adoption and increase value. Increasingly it is becoming clear that there is a link between citizen access to information and changes in clinician patient interaction. This is an important area for future consideration. Roles, workflows and remuneration are also all areas of common interest.

3. Public digital health and health information literacy

Efforts to educate and support people as they engage with their health information and take a greater role in their health care were seen as critical, and present clear opportunities for further study.

4. Evaluation of uptake and impacts

Across countries, there is an acknowledgement that there is insufficient evidence about progress and impacts of citizen access to their information. Measurement activities are mature in a few countries and evolving in others. Sharing evidence presents an early opportunity for collaboration and, in the longer term, the working group may consider collaborating on common indicators or studies.

7 REFERENCES

1. Commonwealth Fund. 2016 International Survey of Adults.2016; accessed at: <https://international.commonwealthfund.org/data/2016/>
2. Doty MM, Tikkanen R, Shah A, Schneider EC. Primary care physicians' role in coordinating medical and health-related social needs in eleven countries: results from a 2019 survey of primary care physicians in eleven high-income countries about their ability to coordinate patients' medical care and with social service providers. *Health Affairs*. 2019 Dec 10:10-377.
3. Fraccaroa P, Vigoc M, Balatsoukasb P, Buchana IE, Peekka N, van der Veerb SN. Patient portal adoption rates: a systematic literature review and meta-analysis. In *MEDINFO 2017: Precision healthcare through informatics: proceedings of the 16th World Congress on Medical and Health Informatics 2018 Jan 31 (Vol. 245, p. 79)*. IOS Press.
4. Zanaboni P, Ngangue P, Mbemba GI, Schopf TR, Bergmo TS, Gagnon MP. Methods to evaluate the effects of internet-based digital health interventions for citizens: systematic review of reviews. *J Med Internet Res*. 2018;20(6):e10202.

Publications shared by submitting countries

Ammenwerth E, Schnell-Inderst P, Hoerbst A. Patient empowerment by electronic health records: first results of a systematic review on the benefit of patient portals. *Stud Health Technol Inform* 2011;165:63-67.

Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: a systematic review of controlled trials. *J Med Internet Res* 2012;14(6):e162.

Davis Giardina T, Menon S, Parrish DE, Sittig DF, Singh H. Patient access to medical records and healthcare outcomes: a systematic review. *J Am Med Inform Assoc* 2014;21(4):737-741.

Essén A, Scandurra I, Gerrits R, Humphrey G, Johansen MA, Kierkegaard P, et al. Patient access to electronic health records: differences across ten countries. *Health policy and technology*. 2018 Mar 1;7(1):44-56.

Goldzweig CL, Orshansky G, Paige NM, Towfigh AA, Haggstrom DA, Miake-Lye I, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann Intern Med* 2013 Nov 19;159(10):677-687.

Hackett C, Brennan K, Fowler HS, Leaver C. Valuing citizen access to digital health services: applied value-based outcomes in the Canadian context and tools for modernizing health systems. *Journal Med Internet Res*. 2019;21(6):e12277.

Irizarry T, DeVito DA, Curran CR. Patient portals and patient engagement: a state of the science review. *J Med Internet Res* 2015;17(6):e148.

Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *J Med Internet Res* 2015;17(2):e44.

Otte-Trojel T, de Bont A, Rundall TG, van de Klundert J. How outcomes are achieved through patient portals: a realist review. *J Am Med Inform Assoc* 2014 Jul;21(4):751-757.

Price M, Bellwood P, Kitson N, Davies I, Weber J, Lau F. Conditions potentially sensitive to a personal health record (PHR) intervention, a systematic review. *BMC Med Inform Decis Mak* 2015;15:32.

van Mens HJ, Duijm RD, Nienhuis R, de Keizer NF, Cornet R. Determinants and outcomes of patient access to medical records: systematic review of systematic reviews. *Int J Med Inform.* 2019 May 17.

Priisalu J, Ottis, R. Personal Control of Privacy and Data: Estonian experience. *Health and Technology* 2017; 7(4), 441-51.

Further links provided by the Netherlands:

- Netherlands Patients Federation: www.patientenfederatie.nl/algemeen/netherlands-patients-federation
- MedMij: www.medmij.nl/en/
- MedMij Trust Framework (English, zipped document set): www.medmij.nl/wp-content/uploads/2019/05/MedMij-Framework-1.1.1.zip
- MedMij FHIR Implementation Guide wiki: http://informatiestandaarden.nictiz.nl/wiki/MedMij:V2019.01_FHIR_IG
- Government booklet explaining how healthcare is organised in The Netherlands: www.government.nl/documents/leaflets/2016/02/09/healthcare-in-the-netherlands
- National government website on digital health: www.government.nl/topics/ehealth
- Nictiz, the national competence centre for ehealth: www.nictiz.nl/english/

8 APPENDIX A: SURVEY INSTRUMENT

Q1. To what extent do citizens in your country have electronic access to their own personal health information?

- Broad availability to all citizens,
- Available to most citizens (more than half)
- Available to some citizens,
- Available to few citizens

CHECK BOX: Access to health information is planned but not yet deployed.
Response to this question and the following responses will reflect those plans

If citizens in your country have current or future planned access to personal health information, please respond to remaining questions.

If not, skip to the last question (Q8) to provide open ended remarks on this topic.

Q2. What kinds of information are most commonly available to citizens. CHECK ALL THAT APPLY

- diagnostic tests results, (e.g. radiology reports/images, laboratory, etc.)
- upcoming encounters or preventative care
- medications, (e.g. actual medication list, medication treatment plan, etc.)
- immunisations, (e.g. current immunisation status, immunisation plan, etc.)
- summaries of encounters or full clinical notes / records
 - Hospital records (summary of full?)
 - Community / primary care records (summary or full?)
 - Outpatient records (summary of full?)
 - Records from other care settings: please name_____ (summary of full?)
- Other: Please name _____

Q3. Approximately what portion of citizens have actually accessed their information (citizen has viewed/downloaded/forwarded information accessible at least once) – i.e. what is the adoption rate

- (PERCENTAGE) _____
- If percentage adoption is unknown, please provide any other contextual information that relates to adoption rate _____

Q4. Is deployment a coordinated or national effort, or is it on an institutional or provider basis (i.e. is there only one place citizens can turn to or are there multiple portals)?

CHECK ONE THAT APPLIES:

- Coordinated or national effort exclusively – i.e. an effort to reach all citizen with a single solution (also check this, if this is not yet the case, but it is the final vision of your national strategy)
- Institutional or provider-based solutions – i.e. different efforts for different organisations / sectors or patients
- Blended: certain services on coordinated/national basis, certain services on institutional/provider basis

Please elaborate if needed: _____

Q5. What were/are the drivers, strategic goals or vision for value from providing citizen access to their personal health information? (SCALE - major driver, minor driver, not a factor, unknown))

- Patient demand / patient centred agenda (major / minor / not / unknown)
- Improving patient engagement and empowerment (major / minor / not / unknown)
- Avoiding unnecessary visits/calls (major / minor / not / unknown)
- Alternate delivery mechanisms for more appropriate use of health system resources (major / minor / not / unknown)
- Specific health outcomes objectives (major / minor / not / unknown)
- Health system / government efficiencies (e.g. reduced bureaucracy) (major / minor / not / unknown)
- Health promotion and disease prevention (major / minor / not / unknown)
- Innovation agenda (government modernisation, encouraging private sector) (major / minor / not / unknown)
- Other please describe: _____(major / minor / not / unknown)

Q6. To what extent are/have impacts associated with these drivers been experienced? (SCALE - to a great extent, Somewhat, to a limited extent, not experienced, unknown)

- Satisfied public (great / somewhat / limited / not / unknown)
- More engaged/empowered patients (great / somewhat / limited / not / unknown)
- Avoided visits/calls (great / somewhat / limited / not / unknown)
- Health System Resource improvements (great / somewhat / limited / not / unknown)
- Specific health outcome improvements (great / somewhat / limited / not / unknown)
- More efficient health system/government (great / somewhat / limited / not / unknown)
- Economic impacts (great / somewhat / limited / not / unknown)
- Unintended patient issues (safety concerns, anxiety, etc.) (great / somewhat / limited / not / unknown)
- Unintended clinician issues (time burden, patient relationship issues) (great / somewhat / limited / not / unknown)
- Other unintended impacts _____ (great / somewhat / limited / not / unknown)

Please describe the most notable positive and/or negative impacts: _____ (OPEN)

Q7. Please describe or provide outputs/evidence from measurement/evaluation/research activities that have contributed to understanding adoption and/or impacts: _____ (OPEN)

Are there other reports, publications, case studies or other evidence related to impacts in your country that you are able to share? (LINKS REQUESTED)

Q8. Do you have any other comments about citizens' access to their personal health information?

Topics may include:

- Future plans for citizen access to personal health information
- Other related e-services for citizens
- Enablers of citizen access to PHI, including:
 - governance and stakeholder roles,
 - policy and legislation,
 - patient engagement and education,
 - markers for adoption such as age, illness burden, geography, related behaviours, etc.
 - barriers/challenges addressed
 - implementation costs/funding health initiatives.

(OPEN)

9 APPENDIX B: OVERVIEW OF RESPONDENT COUNTRY AND TERRITORY HEALTH SYSTEMS

To fully understand and appreciate the efforts of survey respondents to provide access for people to their personal health information, it is important to have some insights into how their health systems are arranged, how they are governed, and how health services are funded and delivered. The following sections provide a general overview of each country's health system governance model as well as electronic health record advancements in the past.

Argentina

Argentina has a fragmented and segmented health system divided into three large sectors – the public, social security, and private sectors (Rubinstein, Zerbino, Cejas, & López, 2018). The public sector is funded by taxes and decentralised to the provinces. The federal Ministry of Health has a rather narrow role in national health policy stewardship. The federal level accounts for about 20 per cent of the public-sector health expenditure. With the exception of a few high-tech tertiary national hospitals, all public hospitals and primary care centres belong to the provinces or municipalities.

The social security sector or Obras Sociales (OS) covers all workers of the formal economy and their immediate families. Most OS operate through contracts with private providers and are financed with payroll contributions of employers and employees. The elderly as well as people with disabilities are covered by a nationwide social health insurance fund for retired workers.

The private sector includes all those private providers offering services to individuals, OS beneficiaries and all those with private health insurance. This sector also includes private insurance agencies called Prepaid Medicine Enterprises, financed mostly through premiums paid by families and/or employers. There is currently no centralised health data repository in Argentina (GDHP, 2018).

Australia

In Australia, three levels of government are collectively responsible for providing universal health care: federal; state and territory; and local (The Commonwealth Fund, 2016). The federal government mainly provides funding and indirect support to the states and health professions, subsidising primary care providers through the Medicare Benefits Scheme and the Pharmaceutical Benefits Scheme and providing funds for state services. It has only a limited role in direct service delivery. The states have the majority of responsibility for public hospitals, ambulance services, public dental care, community health services, and mental health care. Intergovernmental collaboration on the highest priority issues occurs through the Council of Australian Governments (COAG), which includes representation from the Prime Minister and from the first ministers of each state. The Australian Institute of Health and Welfare and the Australian Bureau of Statistics are the major providers of health data. Australia has a number of national collections of patient health information (predominantly billing data) along with a national electronic health record system: My Health Record. Private health services and

research institutes also collect patient health information that may be used for secondary use purposes.

Austria

The Austrian healthcare system is organised by an interaction of public, private non-profit, and private players. The Austrian Constitution stipulates that responsibilities for almost all areas of the healthcare system lie with the federal government (Hofmarcher & Rack, 2001). The responsibility for enacting legislation and implementations in regard to laws governing the hospital sector lies with the nine Länder (states). Delivering healthcare services to the population and controlling the healthcare system is considered to be primarily a public task in Austria. Hence, more than two-thirds of Austria's healthcare system is funded through social insurance contributions and general tax revenue. Approximately one-third is paid by private households directly. Healthcare services are delivered by public bodies, non-profit organisations, for-profit private organisations and individuals.

In 1995, the Austrian Ministry of Health appointed the STRING commission to advise the Minister on all issues related to healthcare telematics. In 2003, the STRING commission recommended that concrete plans be undertaken to introduce electronic health records in Austria. This initiative was entitled ELGA. ELGA was embraced by the Ministry of Health and incorporated into the measures aimed at reforming the Austrian healthcare system. The 2005 Healthcare Reform Act,¹² adopted by Parliament in December 2004, therefore includes a regulation on healthcare telematics (Dorda, Duftschmid, Gerhold, Gall, & Gambal, 2006).

Brazil

Brazil runs a Unified Health System (Sistema Único de Saúde) known as SUS which is based on the Federal Constitution of 1988, which sets out the principles and directives for the delivery of healthcare in the country. The SUS promised universal and comprehensive access to services free at the point of use. Around three-quarters of the population is dependent on SUS, while the rest use the private sector. The bedrock of SUS has been the primary care-based family health programme - Programa Saúde da Família (PSF). It provides preventative and treatment services through Family Health Teams. The state healthcare system is run by the 5,570 municipalities, which are required to invest at least half the tax they collect in healthcare. Funding also comes from the federal government and the 26 states. Some public healthcare is provided by not-for-profit organisations, which make up around 38% of the hospitals. The private and public systems operate almost entirely separately, apart from SUS contracts to private companies for services such as diagnostics. There are also some low-cost walk-in clinics. The Ministry of Health has launched several apps to provide access to personal health records but there is a long way to go.

Canada

The governance of health care is highly decentralised. Provinces have primary jurisdiction over administration and governance of their health systems. Many have established regional health authorities that plan and deliver publicly funded services locally (The Commonwealth Fund, 2016). The federal ministry of health, Health Canada, plays a role in the following: promoting overall health; funding and delivery of certain health services

for First Nations and Inuit; food and drug safety; and medical device and technology review.

The federal government co-finances provincial and territorial programs, which must adhere to the Canada Health Act (1985). The Canada Health Act sets standards for “medically necessary” hospital, diagnostic, and physician services. At the national level, several intergovernmental non-profit organisations aim to improve governance and health system performance (for example, Canada Health Infoway provides funding and support for provincial health information systems). Canada Health Infoway is leading a national strategy to provide people access to their personal health information via the ACCESS 2022 campaign.

Estonia

The healthcare system in Estonia is highly centralised and is governed by the Ministry of Social Affairs and its agencies. The financing of health care is mainly organised through the independent Estonian Health Insurance Fund (EHIF). The EHIF and the Ministry of Social Affairs and its agencies all collect and analyse health data. The Center of Health and Welfare Information Systems operates the e-health system, which is an information-exchange platform that connects all providers and allows data exchange with various other databases. The platform also enables patients to access their health data. The Estonian National Health Information System has been in operation since 2008 and contains more than 20 million different health documents and over 300 million events.

Further information available:

- www.euro.who.int/data/assets/pdf_file/0011/377417/hit-estonia-eng.pdf?ua=1
- www.eiseverywhere.com/file_uploads/c5da2a5e465f932e6debe55020e70899_E-health-factsheet.pdf

Hong Kong SAR

Hong Kong’s healthcare system is modelled after the British NHS system. The Food and Health Bureau is responsible for policies and resource allocation for all of Hong Kong health services (Schoeb, 2016). The public healthcare system is guided by the Hospital Authority and is organised into seven clusters based on geographical location serving the entire population with subsidised medical care. The private hospital system comprising 12 hospitals is loosely associated within the Hong Kong Private Hospitals Association. In 2008, Hong Kong published a proposal to develop a territory-wide patient-oriented sharing system for electronic health records. The electronic health records program is jointly governed by the Food and Health Bureau, the Steering Committee on Electronic Health Record Sharing, and the Program Steering Committee. The first stage of the program took place from 2009–10 to 2013–14.

Further information available:

- www.ehealth.gov.hk/en/about_ehrss/electronic_health_record/ehr_development_programme/history.html
- www.ehealth.gov.hk/en/about_ehrss/ehr_office/governance/index.html

India

India's health sector has been shaped by its federal structure and the federal–state divisions of responsibilities and financing. The states are responsible for organising and delivering health services to their residents. The central government is responsible for international health treaties, medical education, prevention of food adulteration, quality control in drug manufacturing, national disease control, and family planning programs.

In 2015, the Ministry of Health and Family Welfare set up a National Health Portal that provides the public with information on diseases, health services, health programs, and insurance schemes. In addition, a Health Statistics Information Portal has been set up to provide information and data on health indicators, compiled from multiple sources.

There is a policy to establish a federated national health information architecture to roll out and link systems across public and private health providers at state and national levels consistent with metadata and data standards in relation to electronic health records. The policy also envisages leveraging 'the potential of digital health for two-way systemic linkages between primary, secondary and tertiary care to ensure continuity of care. The National Digital Health Blueprint envisages omni-channel access and delivery by a combination of web (India Health Portal), mobile (MyHealth App) and call centres besides social media platforms (Sharma, 2019).

Indonesia

The Indonesian health system has a mixture of public and private providers, and public and private financing. The public system is decentralised with central, provincial and district governments holding different responsibilities. The Ministry of Health is responsible for the management of tertiary and specialist hospitals, setting strategic directions, standards, regulations, and ensuring the availability of financial and human resources. While Indonesia has established a national information system (SIKNAS) that links to district-level health information systems (SIKDA), communication between the systems has been weakened by decentralisation and multiple reporting systems. Vital registration is not complete and is supplemented by regular national sample surveys.

Further information available:

- <https://apps.who.int/iris/bitstream/handle/10665/254716/9789290225164-eng.pdf>

Italy

The Italian healthcare system is mainly public, and it is strongly decentralised on the basis of regional territories. The central government of Italy controls the distribution of tax revenue for publicly financed health care and defines a national statutory benefits package to be offered to all residents in every region. The 19 regions and two autonomous provinces are responsible for organising and delivering health services through local health units. Regions enjoy significant autonomy in determining the macro structure of their health systems. The Ministry of Health is currently divided into 12 directorates that oversee specific areas of health care or supervise the main institutions related to the Ministry of Health.

The New Health Information System (Nuovo Sistema Informativo Sanitario) has been implemented incrementally since 2002, with the goal of establishing a universal system

of electronic records connecting every level of care. It provides information on services, resource use, and costs, but does not encompass all areas of health care; in particular, primary care is not included, while hospital, emergency, outpatient specialist, residential, and palliative care, as well as pharmaceuticals, are (The Commonwealth Fund, 2016).

Further information available:

- www.aehti.eu/advances_vol_1.pdf#page=23

Japan

In Japan, the central government regulates nearly all aspects of the universal Statutory Health Insurance System (SHIS). The national government sets the SHIS fee schedule, and provides reimbursements to local governments, insurers, and providers. It also establishes and enforces detailed regulations for providers. Japan's 47 prefectures (regions) implement those regulations and develop regional healthcare delivery with their own budgets and funds allocated by the national government. More than 3,400 insurers operate components of the SHIS and organise health promotion activities for those insured. Electronic health record networks have been developed only in selected regions in Japan. Interoperability between providers has not been generally established. Currently, the government is working to develop its plan to make personal health information available to patients and providers.

Republic of Korea

Provision of healthcare services in the Republic of Korea is driven by private sector institutions, and National Health Insurance (NHI) which provides universal healthcare benefits to the whole population. The NHI system is operated by the National Health Insurance Service (NHIS) under the supervision and management of the Ministry of Health and Welfare. NHI covers 62.7% (as of 2017) of total medical expenditure. Out of 67,847 medical institutions, 221 are public institutions (as of 2018).

The NHIS is running a national-level online system where citizens can: search and view the results of their general medical appointments; history of visits to medical institutions and pharmacies; and, a history of prescriptions and purchased medications.

Patients also have the legal right to get a copy of their medical records, and medical institutions provide the records in hardcopy or CD format to make it difficult to reuse.

Some private medical institutions allow patients to view personal medical records, including, the results of medical check-ups or their prescriptions, via mobile applications or websites. The number of medical institutions providing such services has been increasing.

To promote the exchange of medical records among healthcare institutions, the government is running the Health Information Exchange (HIE) system. Through this system, citizens can check the history of their personal medical records exchange at MyChart.kr. They can also check the prescription records on the DUR (Drug Utilization Review) system that is run by the Health Insurance Review & Assessment Service.

To build integrated access to personal health information for patients, the Korean government is planning to establish PHR system for the public. The government has allocated 2020 budget to start designing the system and is planning to build the system as soon as possible.

The Netherlands

The healthcare system in the Netherlands is rooted in the “Bismarckian” system. Major healthcare reform in 2006 established a single compulsory insurance scheme in which multiple private health insurers compete for insured persons. All residents are now mandated to purchase insurance policies, which cover a defined benefits package. Insurers must accept all applicants and are expected to contract providers based on quality and price. The government acts as supervisor of the health insurance, purchasing and provision markets aided by watchdog agencies. The national government has overall responsibility for setting healthcare priorities, introducing legislative changes when necessary, and monitoring access, quality, and costs.

Authorities are working to establish a central health information technology network to enable providers to exchange information. All Dutch patients have a unique identification number (burgerservicenummer). Virtually all general practitioners have a degree of electronic information capacity (for example, they use an electronic health record and can order prescriptions and receive lab results electronically). All hospitals currently have an electronic health record. Electronic records, for the most part, are not nationally standardised or interoperable between domains of care.

Further information available:

- www.euro.who.int/data/assets/pdf_file/0008/85391/E93667.pdf?ua=1

Poland

Poland’s health system is based on social health insurance (SHI). The Ministry of Health shares governance and responsibility for health care with three levels of territorial government: municipalities (gmina) are in charge of primary care, counties (powiat) are responsible for smaller hospitals, and districts (voivodeships) for larger hospitals. The Ministry of Health operates the national health institutes and medical university clinics. Private facilities provide mainly outpatient (or ambulatory) care, while the majority of hospitals are public. This diversity of competencies presents considerable challenges for effective coordination of activities across the health system.

Since 2003-04, the National Health Fund (NHF) has been the sole purchaser in the SHI system, but each of the Fund’s 16 district branches manages their own purchasing function.

The use of IT and eHealth solutions in the health sector has been a policy priority for over a decade, but progress has been slow until recently. For example, implementation of ePrescriptions and eReferrals has been postponed a number of times, due to a challenging development of the P1 service platform. Currently however, following a successful pilot, all pharmacies and most of health service providers are connected to the ePrescription service, which is mandatory system-wide as of 2020. Over 95% of prescriptions in Poland are issued in electronic form. Two more important elements of P1 platform have been implemented as well – Patient’s Internet Account and free software for doctor’s practices to issue ePrescriptions and eReferrals. Pilot of eReferral is underway, with the service to be finally launched in 2021. The use of mHealth solutions is low and examples can mainly be found in the private sector, although mobile devices monitoring heart functions have been prescribed by specialists for some years and,

similarly to the other two telemedicine procedures (cardiology and geriatric teleconsultation), are covered by SHI.

Portugal

The Portuguese health system is characterised by three co-existing and overlapping systems: the universal NHS; the health subsystems – health insurance schemes for which membership is based on professional/ occupational group or company; and private voluntary health insurance. The health system in Portugal has an extensive information infrastructure that plays a central role in monitoring system performance. There are electronic platforms (for example, an electronic health data platform) storing different kinds of health information that are used for several purposes. However, not all data sources are effectively connected and some challenges concerning patient privacy and the legal basis for connecting patient data remain. The main source of funding of the Portuguese NHS is general taxation. However, out-of-pocket payments are an important source of financing for the Portuguese health system.

Further information available:

- [www.euro.who.int/ data/assets/pdf file/0007/337471/HiT-Portugal.pdf?ua=1](http://www.euro.who.int/data/assets/pdf_file/0007/337471/HiT-Portugal.pdf?ua=1)

Kingdom of Saudi Arabia

Currently the Ministry of Health is the major government provider and financier of healthcare services in the Kingdom of Saudi Arabia. These services comprise 60% of the total health services in the Kingdom of Saudi Arabia. The private sector also contributes to the delivery of healthcare services, especially in cities and large towns. Implementation of e-health and electronic information systems is already mature (HIMSS Stage 6 and beyond) in a number of hospitals and organizations such as: King Faisal Specialist Hospital and Research Centre (KFSHRC), King Abdulaziz Medical City (KAMC)- Riyadh at the Ministry of National Guard - Health Affairs (NGHA), King Abdullah University of Science and Technology (KAUST), King Khaled Eye Specialist Hospital (KKESH), and Security Forces Hospital - Makkah (SFHM). The National Platform for Health Information Exchange Services (NPHIES) has already launched its Insurance Services, which connect all stakeholders in Health Insurance. The Unified Digital Health Services (Unified Health Record) of NPHIES, is planned to go live on November 2020.

Singapore

The government of Singapore planned, built, and continues to develop and maintain the nation's public healthcare system. It regulates both public and private health insurance in the country. The healthcare system is administered by the Ministry of Health, which has responsibility for assessing health needs and for planning and delivering services through networks of health and hospital facilities, day-care centres, and nursing homes. The Ministry of Health manages, plans for, and maintains staffing throughout the system and is responsible for the financing policies and governance of the public healthcare system. It has overall responsibility for health care, setting policy direction, managing the public healthcare system, and ensuring quality of care and responsiveness of the health system to residents' needs. Its purview includes: needs assessment, services planning, personnel planning, system governance and financing, provider fee-setting, cost control, and health information technology.

Singapore is building a sophisticated national electronic health record system. The system collects, reports, and analyses information to aid in formulation of policy, monitoring of implementation, and sharing of patient records. The long-term goal is to allow medical professionals to access clinical data on patient treatment and safety.

When fully developed, the system will allow data to be accessed and viewed in appropriate formats by medical professionals, patients, and researchers. Data will come from the electronic medical record systems of public hospitals and polyclinics, among other sources. There are plans to enable patients to view and possibly contribute to their personal health records in the near future.

Sweden

All three levels of Swedish government are involved in the healthcare system. At the national level, the Ministry of Health and Social Affairs is responsible for overall health and healthcare policy, working in concert with eight national government agencies. At the regional level, 12 county councils and nine regional bodies are responsible for financing and delivering health services. At the local level, 290 municipalities are responsible for care of the elderly and the disabled. The local and regional authorities are represented by the Swedish Association of Local Authorities and Regions. The health system is highly integrated.

An important policy initiative driving structural changes since the 1990s has been the shifting of inpatient care to outpatient and primary care and the concentration of highly specialised care in academic medical centres. Both the quality of IT systems and their level of use are high in hospitals and in primary care, although the type of systems used vary by care setting and by county council. Nearly all Swedish prescriptions are e-prescriptions. Patients increasingly can access their electronic medical records to schedule appointments or view personal health data, although this access varies among county councils.

Switzerland

The Swiss healthcare system is highly decentralised with responsibilities divided between the federal, cantonal, and municipal levels of government. Cantons play a critical role in its own constitution and its responsibility for licensing providers, coordinating hospital services, and subsidising institutions and individual premiums. The federal government plays an important role in regulating the financing of the system, and other social insurance. The law addressing the national electronic patient record intends to increase care coordination, quality of treatment, patient safety, efficiency in the healthcare system and health literacy of citizens. Insured persons are free to opt into such a record and to decide who is allowed to have access to their treatment-related information. The records are being stored in decentralised form.

Uruguay

The health system in Uruguay consists of a public and a private sector. The institutions in the public sector are the Ministry of Public Health, which provides its services through the State Health Services Administration, the Social Welfare Fund, the University of the Republic, the armed forces and police health services, the municipal governments, and other public and autonomous entities. The private system is made up of Collective Health Care Institutions – roughly 50 prepaid insurance institutions that provide comprehensive

care, private medical care institutions (called partial health insurance institutions), Highly Specialised Medical Institutes (which are public or private enterprises that perform some of the 15 high-tech and/or costly procedures paid for through the Public Resources Fund), and private sanatoriums, clinics, and physicians' offices, together with residences and nursing homes for the elderly. The various public and private institutions purchase services from and sell services to each other, thus creating strong ties among these public and private actors.

Further information available:

- www.paho.org/hq/dmdocuments/2010/Health_System_Profile-Uruguay_1999.pdf
- www.iadb.org/en/improvinglives/how-uruguay-digitizing-its-health-system

United Kingdom

The United Kingdom provides public healthcare to all permanent residents includes the island of Great Britain, the north-eastern part of the island of Ireland and many smaller islands through a government-sponsored universal healthcare system called the National Health Service (NHS). Healthcare coverage is free at the point of need, and is paid for by general taxation. The NHS consists of a series of publicly funded healthcare systems in the UK. It includes the National Health Services (England), NHS Scotland, NHS Wales and Health and Social Care in Northern Ireland. England, Northern Ireland, Scotland and Wales each have their own systems of private and publicly-funded healthcare, as well as alternative, holistic and complementary treatments. Citizens are entitled to healthcare under this system, but have the option to buy private health insurance as well. Each country provides public health care to all UK permanent residents, and each also has a private healthcare sector which is significantly smaller than the public sector.

The NHS assigns a unique identifier to every registered patient. All general-practice patient records are computerised. Since April 2015, GP practices have been contractually obliged to offer patients the choice of booking appointments and ordering prescriptions online. As of March 31, 2016, practices are required to offer patients access to their detailed coded record—including information about diagnoses; medications and treatments; immunizations; and test results. Practices are not required to allow patients access to information that clinicians enter in free-text fields. Where electronic records are not available to patients, such as in dentistry, they can request a paper copy. Records are not routinely linked among providers. The NHS aims to make primary, urgent, and emergency care services paperless by 2023. NHS Choices will serve as a single point of access for patients to register with a GP, book appointments and order prescriptions, access apps and digital tools, speak to their doctor online or via video link, and view their full health record.

United States

Health insurance coverage in the United States remains fragmented even after the enactment of the Affordable Care Act in 2010 with numerous private and public sources, as well as wide gaps in insured rates across the US population. Private health insurance is regulated at the state level.

The 2009 American Recovery and Reinvestment Act led to significant investment (more than US\$30 billion) in health information technology. The legislation established financial incentives for physicians and hospitals to adopt electronic health record systems, under what is known as the EHR Incentive Program. As of 2015, 84 per cent of physicians used some form of electronic health record system, and three out of four hospitals (76 per cent) had adopted at least a basic system, representing an eightfold increase since 2008.

The Meaningful Use Incentive Program is designed to gradually raise the threshold for electronic health record functionality above which providers receive incentives and avoid penalties. The current focus is on information exchange.

Under the 21st Century Cures Act, Health IT developers will have to follow new requirements on application programming. There are requirements for the development of application programming interface, or API, technologies that are more standardised and easier for patients to access. The 21st Century Cures Act requires health IT developers to publish APIs that allow health information from such technology to be accessed, exchanged, and used without special effort through the use of APIs. In addition, the Act requires that a health IT developer must, through an API, provide access to all data elements of a patient's electronic health information.

Furthermore, the 21st Century Cures Act requires healthcare providers to do their part too. The new API standards will in turn allow hospitals and other health care providers to more easily share EHI — as long as they are equipped with the technology that allows them to comply.

Further information available:

- https://international.commonwealthfund.org/countries/united_states/
- <https://www.fda.gov/regulatory-information/selected-amendments-fdc-act/21st-century-cures-act>

